

**FOCUS****HEALTH INFORMATION EXCHANGE:**  
Case Studies in Interoperability and Integration

# State Health Information Exchange

## Factors Shaping Sustainability and Value

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### ABSTRACT

The economic sustainability of health information exchanges (HIE) presents formidable hurdles. HIEs share common economic and public good characteristics with other networks that public policy classifies as a public utility. The value of HIEs accrues to diverse and sometimes competitive stakeholder groups. HIE value is complex to measure and in some cases does not begin to accrue until a critical mass is achieved. Further, a lack of consumer trust and fears of inadequate security of patient records are major barriers to the success of both HIE adoption and the variety of application offerings. Finally, existing health system enterprise HIEs and regional HIOs can both complicate and enhance the development of interoperable and sustainable networks.

The Office of the National Coordinator for HIT provided funding for the initial development of state HIEs. However, these grants require strategic and operational plans that must include economic sustainability. This study suggests a stakeholder segmentation, identification of value propositions and potential value equations for stakeholder groups, and develops them within the context of economic, regulatory, privacy and security barriers faced by HIEs.

### KEYWORDS

State health information exchange, public utility, sustainability, privacy, trust, value propositions, participation agreements.

**H**EALTH INFORMATION exchanges (HIE) are networks offering unique and complex services that provide the backbone for the meaningful use of health information technologies. The Office of National Coordinator for Health Information Technology (ONC) is funding the rapid build-out of HIEs through \$547 million in grants over four years through the [State HIE Exchange Cooperative Agreement Program](#).<sup>1</sup> Beyond technical requirements, key elements of the grants focus on policies and economics, including governance, business operations, financing mechanisms and overall sustainability.

The principles shaping ONC's approach to HIEs are:

- Support privacy and security.
- Achieve desired outcomes (meaningful use).
- Support services and adoption for all relevant stakeholders.
- Be operationally feasible and achievable.

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- Vigilance and adaption to emerging trends and developments.
- Foster innovation.

State operational plans are required to ensure that all eligible providers have at least one viable option to meet Stage I meaningful use in 2011. ONC HIE principles require universal access within the state for all “stakeholders including providers in small practices, and across a broad range of uses and scenarios,” while at the same time being financially sustainable, robust and flexible enough to grow in innovative ways yet unknown.<sup>2</sup> State HIEs must also support recent health reforms. For example, information exchange will be critical to Accountable Care Organizations for Medicaid beneficiaries.

Both the evolving market structure and governance of HIEs are critical to reaching these goals. As a network-based service, HIEs can be examined within the larger framework used to analyze network industries. The history of the predecessors to HIEs, CHINs and RHIOs, is one of failure or marginal sustainability.<sup>3</sup>

Going forward, given the implementation and meaningful use of electronic health records by a critical mass of clinicians and institutions, the prospects for HIEs appear much improved. However, this rapid evolution is resulting in an uncertain market structure. In addition, security, privacy and trust must be established with all stakeholders and is a potential major constraint. Finally, sustainability must be driven by the value derived by stakeholders in this dynamic environment.

### ARE HIES A PUBLIC UTILITY?

When considering HIE governance, as depicted in Table 1, HIEs have several characteristics associated with public utilities: 1. Potential barriers to entry that can result in a natural monopoly; 2. A product or service that is considered a “public good” with the need for universal access; and 3. No close product substitutes.<sup>4</sup>

### BARRIERS TO ENTRY

Once established, HIEs may evolve to have characteristics that could result in barriers to entry and a natural monopoly. One

**Table 1: Potential Economic Factors Shaping HIEs**

Category	Structural Issue
<b>Network Effects</b>	The greater number of users, the greater the value of connectivity.
<b>Network Bottlenecks</b>	Databases, repositories or critical applications controlled by a single system operator.
<b>Economies of Scale</b>	Globally sub-additive cost structure result in a natural monopoly.
<b>Public Good Product</b>	Public interest in the service with a requirement for universal service.
<b>Product Substitutes</b>	Lack of product alternatives that can be used in lieu of HIEs.

barrier is the network effects of having a critical mass of users such that the largest provider attracts the most users and has a competitive advantage, the more individuals using a service the greater the value to users, such as Microsoft Office. Network effects have been a common experience in industries using the Internet/VPN as a means of distributing services.<sup>5</sup>

A second potential barrier concerns the ownership or operation of a bottleneck for services and applications provided by the network. For example, this could be the control of databases or registries that provide patient data, or control of a service that is an integral part of HIE.

A third potential barrier to entry is that within their relative geographic market, many network-based industries exhibit substantial economies of scale such that the largest provider has the lowest costs and inherent competitive advantages.<sup>6</sup> This would result in only one provider being viable. Absent policy oversight, these barriers to competition could result in market failure and the ability to extract economic rents through transaction or access fees.

### PUBLIC GOOD PRODUCT

HIEs appear to have obvious public good characteristics. Similar to water or power there is a value to all citizens to have access to electronically networked healthcare to capture the potential for improved care, better access and lower costs. Associated

with this public good issue is another factor for public utility classification, no close product substitute. If an entity achieves an advantaged position in the HIE network, users have no alternative products or services to turn to.

Thus, HIEs have many elements similar to public utilities. This suggests a key role for public policy oversight.

### HIE GEOGRAPHIC AND PRODUCT MARKETS

The principal geographic region for the actual exchange of health information is a medical trade area (MTA). This was the basis for the original HIE initiatives being regional efforts in the form of RHIOs.

However, states rather than regional entities appear the appropriate controlling authority for both economic and regulatory reasons. First, universal access, particularly to underserved populations, would be difficult to achieve without state offerings or requirements. Second, states have vested economic, policy and scope-of-control interests in Medicaid and public health. Third, allocation of grants directly to regions instead of states would be logistically impractical. Fourth, to ensure cooperation by the players and protect against potential anticompetitive behavior, state regulation may be required. Fifth, to develop a sustainable business model, regulation derived from the state authority may be required.

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Figure 1 provides segmentation for the key entities involved in providing HIE services. How they will ultimately fit into the evolved HIE structure is unclear and will depend on the approaches taken by individual states.

In funding state HIE's, ONC has indicated a flexible policy approach. States may either act by facilitating services or may directly offer services.<sup>7</sup>

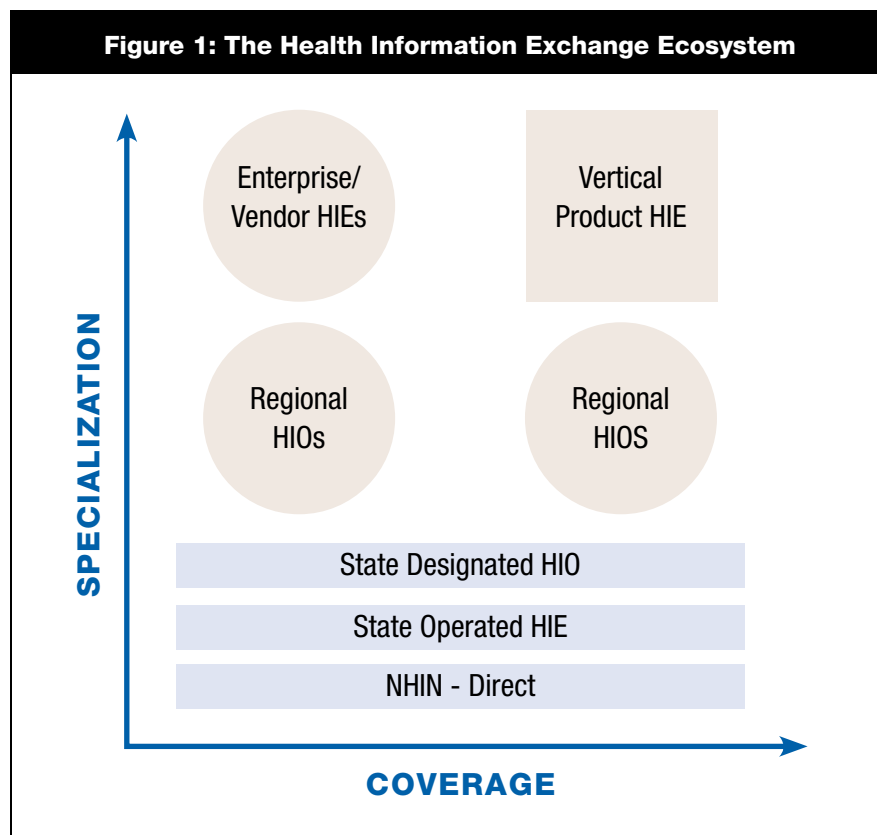
The relationships among the entities in Figure 1 are potentially highly complementary. The key is the integration of these players into a framework that encourages cooperation. ONC requires a broad transparent multi-stakeholder process in the development of state HIE plans to facilitate coordination and optimization. A summary of the segmentation for HIE entities is below.

**NHIN-Direct.** The NHIN Direct project develops specifications for a secure, scalable, standards-based way to establish universal health addressing and transport for participants (including providers, laboratories, hospitals, pharmacies and patients) to send encrypted health information directly to known, trusted recipients over the Internet.

It is a stripped-down version of the Nationwide Health and Information Network (NHIN). NHIN Direct itself will not run health information exchange services. The NHIN Direct project will expand the standards and service descriptions available to address the key Stage I requirements for meaningful use, and provide an easy "on-ramp."<sup>8</sup>

**State-Operated HIEs.** HIEs provide the infrastructure for information exchange, including the business model, governance structure, operating principles, legal model and technology model for the exchange of health information among various organizations.

A state-operated HIE is modeled more like a public utility which has various stakeholders from both public and private realms. State operated HIEs are recognized as a public good that will create value and serve the needs of its citizens and therefore, must achieve critical mass to become useful. The strength of the partnership



between public and private stakeholders plays a crucial role in attaining critical mass and the success of the exchange.<sup>9</sup>

**State-Designated HIOs.** Include not-for-profit organizations with broad stakeholder representation on its governing board designated by the state as eligible to receive awards under the cooperative agreement.<sup>10</sup>

**Regional HIOs.** HIOs that govern health information exchange within a defined geographic area, typically adjacent medical trade areas. Most RHIOs were in existence before the HIE cooperative grant program. Some RHIOs have been designated as SDEs under the cooperative agreement.

**Health System Enterprise HIEs.** Initiatives that pass health information across one or multiple health enterprises. Enterprise HIEs bring together stakeholders to implement standards by developing a framework for interoperability. An enterprise HIE can be an intranet or interconnect with locations external to a health system.<sup>11</sup>

**Vendor HIEs.** Vendors are offering HIE solutions on an open network basis to their customers and others. In some markets certain vendors are the primary providers and can and have a strategic point of entry for launching HIEs.

**Vertical Service HIE.** Vertical services are engaged when a third-party entity manages and distributes targeted solutions to one segment of HIE, to customers across a wide area network from a central data center; such as e-prescribing.

In dealing with the range of potential providers, besides technical harmonization, challenges include governance to maximize cooperation and minimize economic market power such as data or service bottlenecks. Sustainability of HIE will be a challenge and care must be taken to guard against any entities siphoning-off scarce revenues due to network structural inefficiencies.

Approaches are being developed to deal with this evolving market structure. For example, Minnesota has recently passed

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legislation that requires certificates of authorization for two classes of entities involved in health information exchange:<sup>12</sup>

**Health Information Organizations.** Entities involved in operating health exchanges.

**Health Data Intermediaries.** Entities involved in some components of the health information exchange such as vendor networks.

**PRIVACY, SECURITY  
AND TRUST AS BARRIERS**

HIE adoption and use is being shaped by concerns for privacy and security and the overall issue of trust by consumers, clinicians and institutions. The concern, and sometimes mistrust, by these key participants hinders the overall goal of an exchange: to improve the health outcomes for all patients. It is an additional detriment to attaining critical mass.

While the advocate's vision remains that an HIE will assist with the delivery of improved medical services, the market pragmatist understands the necessity for participants to trust the health information exchange to transmit electronic health records in a secure environment under defined parameters. To address disparities, the ONC is at the forefront providing guidance to states with a particular focus on privacy and security issues. However, some of the methods to fulfill the exchange process are deterred by obsolete state laws.

**ONC GUIDING PRINCIPLES**

To bridge the gap in the areas related to privacy and security, the ONC adopted a fair information practice to instruct the handling of personally identifiable health information and alleviate this potential barrier. This document, the Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information, is a set of principles that provide the privacy and security goals for HIOs operating in the nation. The principles include:<sup>13</sup>

- Openness and transparency.
- Collection use and disclosure limitation.
- Data quality and integrity.

**THE PRIMARY FOCUS** of sustainability should be on sustaining information sharing efforts, and not necessarily the persistence of government-sponsored health information exchange entities. ONC anticipates that annual updates to the state plans will provide further developed approaches and activities for long-term HIE sustainability.

- Safeguards.
- Accountability.
- Individual access.
- Correction.
- Individual choice.

While the ONC listed eight principals in the framework, the last three on the list could generate volumes of for discussion regarding nuances under the umbrella of consent. Without dismissing the significance of consent, but to maintain a manageable scope, this study focuses on the top five principles established by the ONC. By the analysis of these five principles, many of the ONC's objectives can be met in a preliminarily and nascent manner by an HIO through the drafting and enforcing effective agreements.

Participation agreements (PA) are the legal document that sets the terms of the healthcare providers' membership in the healthcare information exchange.<sup>14</sup> Providing a sound legal foundation, an effective PA adheres to the principals of the framework and eliminates legal barriers to the establishment of trust. There are five of the principles identified in the framework as

they relate to these agreements.<sup>15</sup>

The first principal is openness and transparency which indicates there should be openness and transparency about policies, procedures, and technologies that directly affect individuals and/or their individually identifiable health information. The HIO's PA should provide for policies and procedures that safeguard the privacy and security of the data. In signing the agreements, each provider must indicate they are a HIPAA-covered entity, thereby affording all another providers the assurance that their data are subject to the same legal protections. The HIO's obligation to maintain HIPAA compliance in an accessible and comprehensive manner helps quell concerns about security, and thereby improves the potential for attaining critical mass.

The second principal applies limitations on individually identifiable health information in the areas of collection, use and disclosure of the data only to the extent necessary to accomplish a specific purpose.

The HIO's PA should include language that the data received from providers will

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## HEALTHCARE IS A REGIONAL business and there are unique characteristics within each state. Thus, there is not a universal solution for HIE governance or public policies.

only be used for treatment, payment and operations or for any other purposes consistent with HIPAA. More specifically, downstream agreements or business associate agreements should set boundaries on the use of de-identified individual health information, retention policies and data security practices. Identifying acceptable use establishes the parameters of purposes for which electronic health information can be accessed. By restricting the use of the data, participants are reassured that privacy and security of individually identifiable health information will not be used to discriminate inappropriately.

The third and fourth principles are closely related and can be discussed together. Data quality and integrity requires persons and entities take reasonable steps to ensure that individually identifiable health information is complete, accurate and up-to-date to the extent necessary for the person's or entity's intended purposes and has not been altered or destroyed in an unauthorized manner.

Similarly, responsibilities under the safeguards principle protect individually identifiable health information with reasonable administrative, technical and physical safeguards to ensure confidentiality, integrity and availability and to prevent unauthorized or inappropriate access, use or disclosure. The PA can illustrate these principles by calling for adequate credentialing of provider employees and anyone accessing the exchange through provider portals. Steps taken to validate patient records for quality and that transmitted patient records are the same as those maintained by the provider add another layer of protection.

The fifth and final privacy and security principle reviewed here is accountability. Accountability implements procedures, such as monitoring and auditing methods, to report and mitigate non-adherence breaches. This includes:

- Authentication and authorizations for access to or disclosure of individually health information.
- The availability to receive and act on complaints, including corrective measures.
- Reasonable mitigation measures, including notice to individuals of privacy violations or security breaches that pose substantial risk or harm.<sup>14</sup>

Accountability is its own category; however, the reporting arm does lend itself to the first principle, openness and transparency. Where third-party service organizations have access to individually identifiable health information, a business associate agreement must be in place to ensure compliance with HIPAA.

Similarly, the HIO operates as a business associate to the provider and as such, should enter into an agreement with the provider. This guidance is provided by 45 CFR parts 160 and 164<sup>16</sup> and section 13408 of the HITECH Act.<sup>17</sup> By being a business associate the HIO has all legal responsibilities and obligations to protect the privacy and security of the data under HIPAA and the HITECH Act.

Thus, using the ONC framework many privacy and security concerns by key participants are suppressed by an effective PA or business associates agreement. Yet, those are not the only concerns recognized as barriers to establishment of HIEs. In short, the PAs and business associate

agreements have to operate in conjunction with state laws that effect personal health information.

### STATE LAWS

States laws vary significantly in their compatibility with the evolution of HIOs and the permissible exchange of medical records in electronic format. This is problematic because state laws are not uniform and may fail to support technological advancements in healthcare. The underlying premise is that paper-based state laws and inconsistent state laws act as a barrier to the seamless implementation of eligible providers' ability to utilize health information exchange.

There are several areas of law that can be highlighted to draw attention to these irregularities. Yet, e-prescribing laws are at the forefront. On July 6, 2010, ONC released a Program Information Notice to all State Health Information Exchange Cooperative Agreement Program Award Recipients naming e-prescribing as one of the three deliverables for the states' strategic and operational plans through 2011.<sup>18</sup> As such, e-prescribing is being heavily scrutinized in an effort to meet the new standards and is the prime example of state laws that thwart the transition from paper to electronic records.

Assuming that state laws will allow the prescription to be transmitted to the pharmacy electronically, there are numerous state laws that require the pharmacist, upon receipt of the prescription, to reduce the electronic prescription to writing. For example, Kentucky, KRS 218A.180(6) requires all oral or electronic prescriptions

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to be immediately reduced to writing.<sup>17</sup> Kentucky is not alone in this practice. Alaska, Montana, Nevada, New York and Ohio<sup>18</sup> also require paper copies of electronically received prescriptions. Reducing electronic prescriptions to paper is an expensive duplication of resources and disruption of the pharmacy workflow. It counters the efficiency of e-prescribing.

A secondary barrier to adoption of health information exchange is areas of the law that cause heightened concern for privacy and security. These laws include the handling of certain categories of personal health information that are considered particularly sensitive and that may have special protections. These areas relate to substance abuse, HIV/AIDS, sexually transmitted diseases and mental health records. The following statutes are examples of HIV state laws that require interpretation of exactly who is providing care and what type of care before a determination can be made if a release of the records is proper.

In Ohio, the disclosure of HIV test results are permitted to a healthcare provider who has a medical need to know the information and who is participating in the diagnosis, care or treatment of the individual on whom the test was performed. Similarly, Kentucky requires that HIV test results may be disclosed to the physician, nurse, or other healthcare personnel who have a legitimate need to know the test result to provide for his protection and to provide for the patient health and welfare. Missouri echoes Kentucky law in that HIV results may be provided to healthcare personnel working directly with the infected individual who have a reasonable need to know the results for the purpose of providing the direct patient healthcare.<sup>19</sup>

The special protection by state statutes and regulations is due to the social stigma associated with the conditions and the potential consequences stemming from the inadvertent disclosure of the information contained in the records. Yet as with e-prescribing laws, there is great variance in the standards for release of the test results. While the areas outside of e-prescribing do not have the added impact of being key deliverables for states, they expose another

**Table 2: Examples of Stakeholders and Value Propositions**

Stakeholder Group	Domain
<b>Healthcare Providers</b>	<b>Improved Care</b> <ul style="list-style-type: none"> <li>Chronic disease management</li> <li>Integrated continuum of care</li> <li>Interventions</li> </ul> <b>Increased Productivity</b> <ul style="list-style-type: none"> <li>Lower FTEs</li> <li>Timeliness of information</li> </ul> <b>Reduced Costs</b> <ul style="list-style-type: none"> <li>Redundant tests</li> <li>Admissions/ED usage</li> <li>Formulary</li> <li>Length of hospitalization</li> </ul> <b>Strategic</b> <ul style="list-style-type: none"> <li>ARRA compliance</li> <li>Claims processing</li> <li>Claims denial visibility</li> </ul>
<b>Payers, Purchasers, Self-Insured</b>	<b>Reduced Costs</b> <ul style="list-style-type: none"> <li>Redundant tests</li> <li>Formulary</li> <li>Transition of care</li> <li>ED usage &amp; readmissions</li> <li>Chronic disease management</li> <li>Administrative (HEDIC, etc.)</li> </ul> <b>Member/Employee Health</b> <ul style="list-style-type: none"> <li>Incentive model</li> <li>Wellness</li> </ul>
<b>Government &amp; State Entities</b>	<b>Reduced Costs</b> <ul style="list-style-type: none"> <li>Medicaid</li> <li>Underserved/vulnerable populations</li> </ul> <b>Public Health</b> <ul style="list-style-type: none"> <li>Surveillance</li> <li>Intervention</li> </ul> <b>Quality of Care</b> <b>Quality of Life</b>
<b>Patient/Caregiver</b>	<b>Improved Quality</b> <b>Lower Costs</b> <b>Improved Access</b> <b>Improved Experience</b> <b>Medical Home</b>
<b>HIT Vendors</b>	<b>Collaboration</b> <b>Proposal Opportunities</b>



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## ONCE ESTABLISHED, HIEs may evolve to have characteristics that could result in barriers to entry and a natural monopoly.

body of law in which there is a possibility of erosion of confidence from participants.

### **FUTURE OF HIE PRIVACY AND SECURITY FRAMEWORK**

Attaining a critical mass likely begins with identifying privacy and security concerns and working to eliminate them. When the concern is about data use or security, a sound legal framework of agreements should drive the solutions. However, inviting those key participants, especially those with the greatest concerns, could prove the biggest bridge to trust. When openness and transparency is extended at the outset, it tends to lessen the need for later refinement and explanation. Making key participants feel comfortable with the HIO development may include: open discussions about the ONC principles, shared drafting ideas for the PA and business associates agreement, and identification of areas of state law in which the practice and the law do not meet, or fail to support HIO efforts. By utilizing this approach, public buy-in and value are established through an active stakeholder alliance at the outset of HIE operation.

### **STAKEHOLDER SEGMENTATION AND VALUE PROPOSITIONS**

There is no silver bullet for HIE sustainability. The track record of CHINs and RHIOs make that apparent. Sustainability approaches must weigh the value associated with HIE's and fund the service such that contributions are made in a way that is proportional to the economic benefit received within the context of the timing of accrual of the benefits across stakeholders.

Table 2 details representative stakeholders that have been identified in publicly available state HIE filings with the ONC. These stakeholders represent broad interests and have different value propositions.

At the highest level these potential benefits include quality improvement, evidence-based medicine, pay-for-performance, patient education, transition-in-care improvement, disease surveillance, productivity improvements, billing efficiencies and others. To engage stakeholders and develop a rationale for HIE fee structures there is a need to develop value propositions and derive their associated value equations. Documented and targeted communication programs are necessary to approach each shareholder group.

The problem is not with identification of the value propositions, but with the monetization of the value equations. There are two primary sources of data available to assist in the development HIE value equations. The first are the research studies and white papers that drill down and attempt to place value on EHR's and components of the infrastructure. The second are the rates and payment structures charged by existing HIOs. Both of these sources are severely limited because they have been developed in a context of limited EHR penetration and constrained network functionality.

For the initial submissions of state HIE plans the ONC recognized the challenges of developing sustainability models. Applicants are only required to describe initial thoughts on the methods of achieving sustainability and provide analysis of any tests on revenue models. Primarily, the publicly available state filings at the time of this writing have focused on stakeholder engagement, the development of value propositions, and the identification of revenue categories.

Whatever approach, a quantification of the HIE value proposition is necessary in order to assess the economic costs and benefits of the networks. Table 3 suggests the

type of measurement that can be extrapolated to provide a foundation to establish the value equation associated with the value propositions.

### **PUTTING IT TOGETHER: THE EVOLVING HIE MARKETPLACE, PUBLIC POLICY AND SUSTAINABILITY**

HIEs present particularly complex economic problems. Unlike most network services, the economic value is diffuse, accrues over time and is difficult to measure. Given that HIEs have many characteristics of a public utility, with the associated risk of the evolution of an anti-competitive market structure, a high degree of vigilance is required during these early days of development. Achieving critical mass is crucial to the success of an exchange; wherein the utility cannot be met unless a meaningful number of participants are engaged. To this end, efforts to allay insecurities surrounding privacy and security that negatively affect participation will further the success of HIOs. HIEs will be a network of networks, with the interrelationship of the potential pieces continuing to evolve.

Healthcare is a regional business and there are unique characteristics within each state. Thus, there is not a universal solution for HIE governance or public policies. Moreover, the variance of state laws makes the functionality of each HIE different; having an unlevel legal landscape fails to foster confidence in the HIEs capabilities for secure transfer of personally identifiable health information. At its most basic, ONC requirements only require universal access to support the evolving meaningful use standards and the associated goals for improved care, better patient access and downward shifting cost curves. It is up to the states to engage stakeholders and develop sustainable HIEs to shape an efficient market structure either through cooperation, competition, regulation or a combination thereof.

In developing sustainable HIEs, a basic guiding principle can be stakeholder financial support of the network in proportion to the value derived. Part of that value and time must be spent on the development of a sound legal foundation to cultivate an envi-

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ronment. Stakeholders need legal affirmation in the form of inclusive PAs that they themselves have had a hand in drafting.

The ONC requirement of the transparent engagement of stakeholders provides the framework for engagement and the ability to derive consensus value propositions and associated value equations. This process provides a bottom-up approach to a monetization of the value of HIEs and a transparent means of establishing pricing and other types of revenue sources. There is substantial research to provide a foundation for these analyses. Engagement of stakeholders in these analyses can provide validation and buy-in. **JHIM**

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